Patient Consent Management:
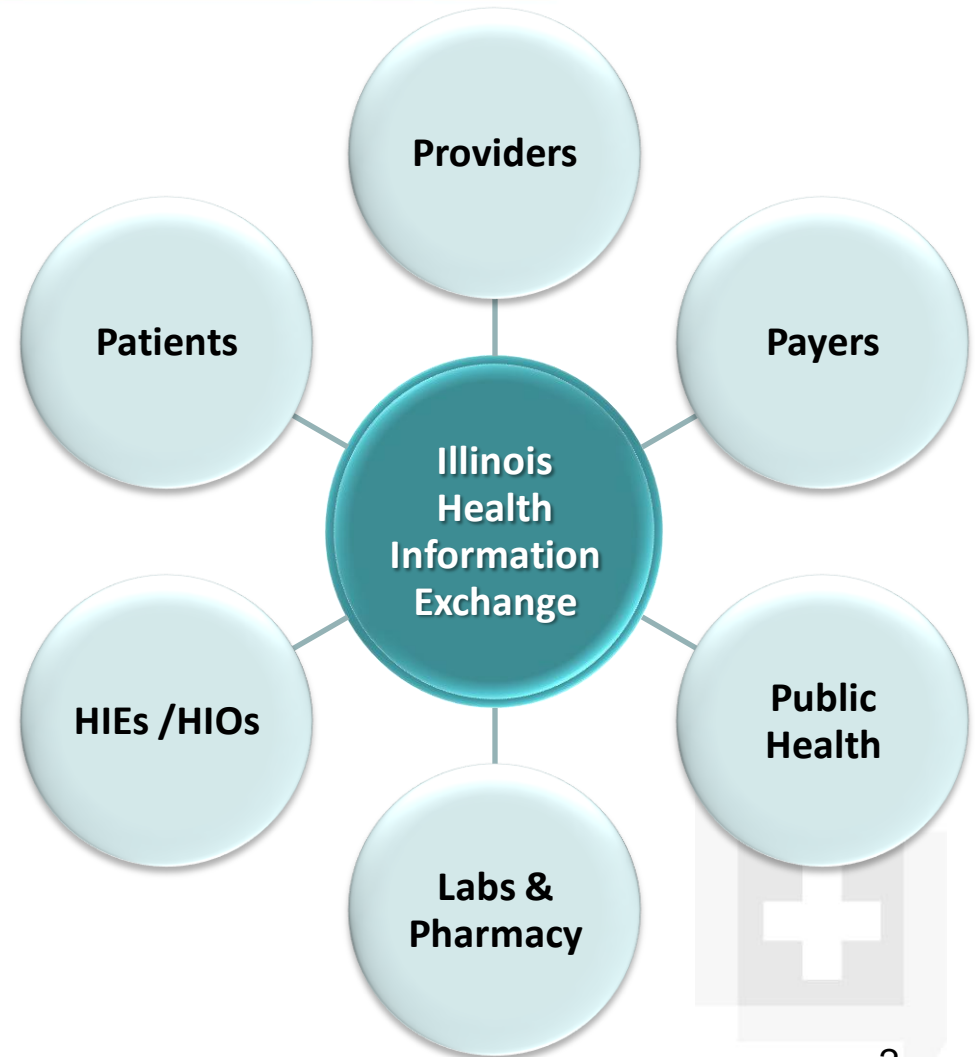*What is it? Why does it matter?*

BHIP Second Statewide Meeting
Thursday, November 1, 2012

Mark Chudzinski, General Counsel
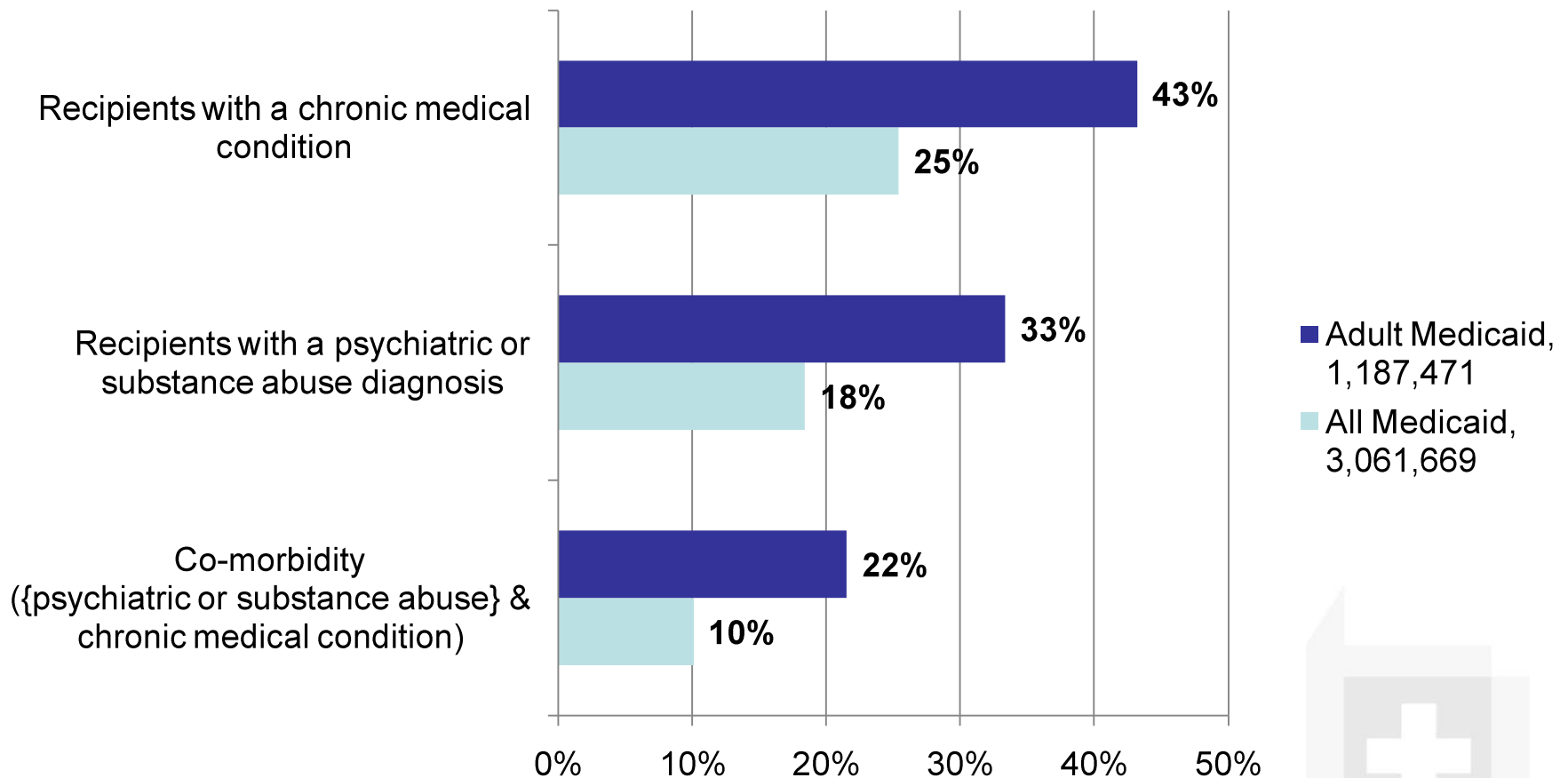Illinois Office of Health Information Technology
Office of the Governor

HIE network hub concept

Secure, effective, and efficient exchange of health information in compliance with state and federal standards, laws, and regulations

2

Behavioral Health Disorders in the Medicaid Population

Recipients with a chronic medical condition
- Adult Medicaid: 43%
- All Medicaid: 25%

Recipients with a psychiatric or substance abuse diagnosis
- Adult Medicaid: 33%
- All Medicaid: 18%

Co-morbidity ({psychiatric or substance abuse} & chronic medical condition)
- Adult Medicaid: 22%
- All Medicaid: 10%

Legend:
- Adult Medicaid, 1,187,471
- All Medicaid, 3,061,669

X-axis: 0% 10% 20% 30% 40% 50%

Source: Illinois Department of Healthcare & Family Services, October 2012

Sharing of Clinical Data Is Key

- Health care ecosphere is complex
- Successful treatment of a single patient involves multiple parties
  - Clinical treatment is delegated among multiple specialists
  - Location of clinical treatment is distributed among different types of facilities during patient's course of treatment
  - Payment for treatment from multiple sources
  - Management of multiple parties and processes requires evaluation systems which measure and assess results

Goals of the Illinois Health Information Exchange

- Improve health care quality and outcomes

- Control the cost of health care and enhance value for patients and payers

- Maximize federal health information technology funding to Illinois and its health care providers

- Enhance public health and disease surveillance; reduce disparities

ILHIE Act: Protection of patient privacy & security

➢ "The Authority shall establish minimum standards for accessing the ILHIE to <u>ensure that the appropriate **security and privacy protections** apply to health information</u>, consistent with applicable federal and State standards and laws."

➢ Dec. 1, 2011: Formation by ILHIE Authority Board of Data Security and Privacy Committee

"The Committee's role is to review, evaluate and recommend **ILHIE data privacy and security policies**, and to oversee the development of new ILHIE data privacy and security policy recommendations with appropriate collaboration with State of Illinois stakeholders, policy developers and implementers."

ILHIE DSPC Deliberations

- Testimony of 30+ stakeholder representatives and members of the general public
  - All proceedings public
  - 5 sets of hearings (2/8, 3/29, 5/3, 7/17, 7/28)
  - Input from health care services providers and consumers; 4 RHIOs; subject matter experts
  - 450+ pages of publicly- posted documents

Barriers to HIE in Current Laws

- MHDDCA requires patient consent with considerable specificity for release of data
  - Prohibits "blanket consent"
  - Prohibits "advance consent"
  - Durational limit on consent

- MHDDCA application unclear and arguably restricts data aggregation query-response HIE to disclose data without a new consent at the time of each data release
  - Future data recipients not known (at data creation)
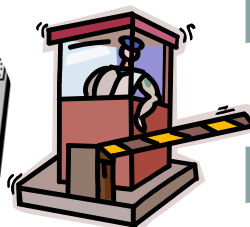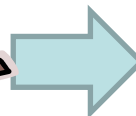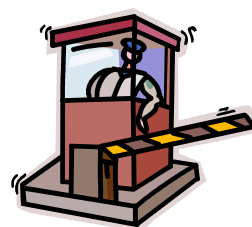 - Date of future data release not known

MetroChicago-HIE data filters

MetroChicago-HIE data filters

"Excluded data": mental health; substance abuse

"Highly Confidential data": HIV/AIDS; genetic testing

HIE

Excluded data:	Confidential data:	Opt-out:
Mental health;	HIV/AIDs;	All data
Substance abuse	Genetic testing	

Report of Preliminary Findings & Recommendations

- 67-page report, including 5 exhibits
- 28 numbered Findings & Recommendations
  - Grouped into 20 categories

Core Commitment to Privacy and Security	Opt-Out Override/ Break-the-Glass
The Importance of Information Sharing	Continuation of "Opt-In" under Current Laws
The Role of HIT Technology	Administrative Burdens
National Interoperability	Barriers to HIE in Current Laws
Harmonizing Illinois Law	Future Segmentation of PHI
Meaningful Use Incentives	Data Security Protections and Assurance
Efficiency	Control of Data by Data Custodians
Public Health	Neutrality on Merits of Data Custodian Disclosure Restrictions
Balancing of Stakeholder Interests	Unique Patient Identifier
Enhancing Patient Protection: Opt-Out Policy	Next Steps

5 Key Preliminary Findings & Recommendations

1. Multi-staged approach to implementation of ILHIE and the privacy & security policies which current technology enables

2. Harmonization of IL law with Federal law (e.g. HIPAA); amend IL laws
   – Reduce IL law uncertainty
   – Look to Federal law leadership to facilitate national HIE inter-operability

3. Encourage flow of PHI into HIE for HIE purposes, but provide patient privacy protection with patients being given "opt-out" choice for HIE participation

4. Since PHI segmentation is currently not technically practical, launch the ILHIE with an "all-data-in or all-data-out" patient choice, but as technology matures, introduce more granular patient choices for what PHI patients wish to share with whom

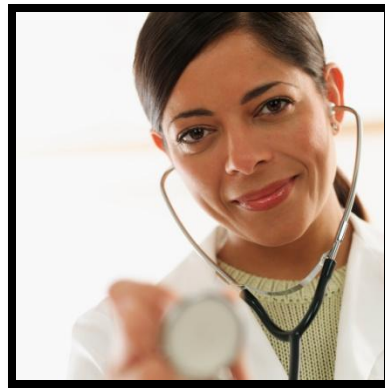5. Adopt measures to build provider and patient trust in the ILHIE

Stage 1: Creation and Release of PHI
Patient Presents at Primary Care Physician
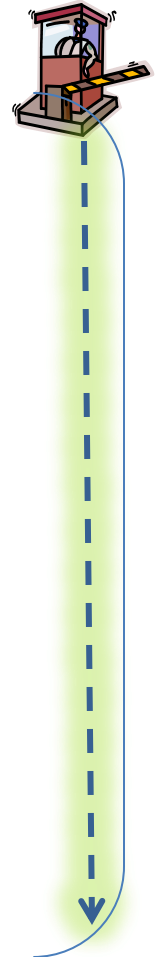
1. Patient presents at Primary Care Physician

2. Provider describes HIE and offers opt-out

PCP's EHR

Gen PHI

ILHIE
Illinois Health Information Exchange

HIE

Use Case 1: Patient Participates in HIE

Stage 1: Creation and Release of PHI
Provider Obtains Consent

3. Patient does not opt-out
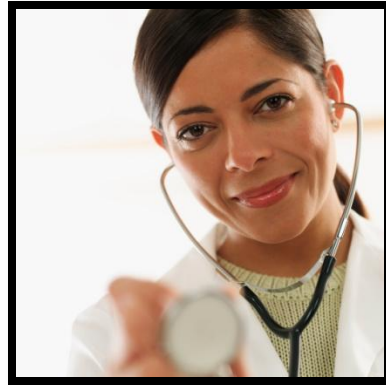
PCP's EHR
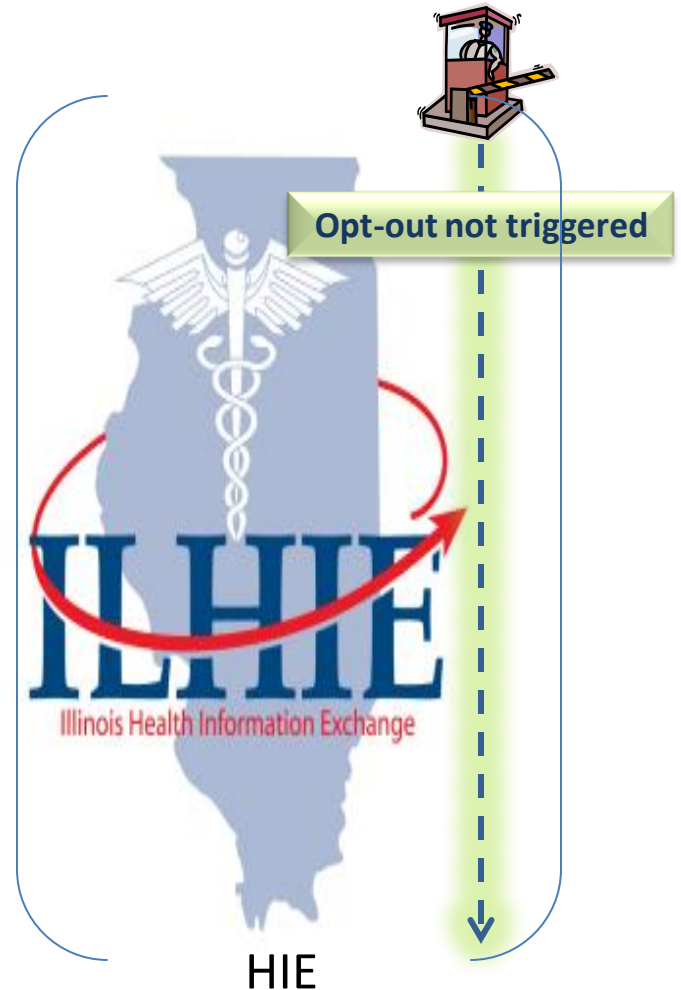
Gen PHI

Opt-out not triggered

HIE

Use Case 1: Patient Participates in HIE

13

Stage 1: Creation and Release of PHI
Release of MPI and RLS
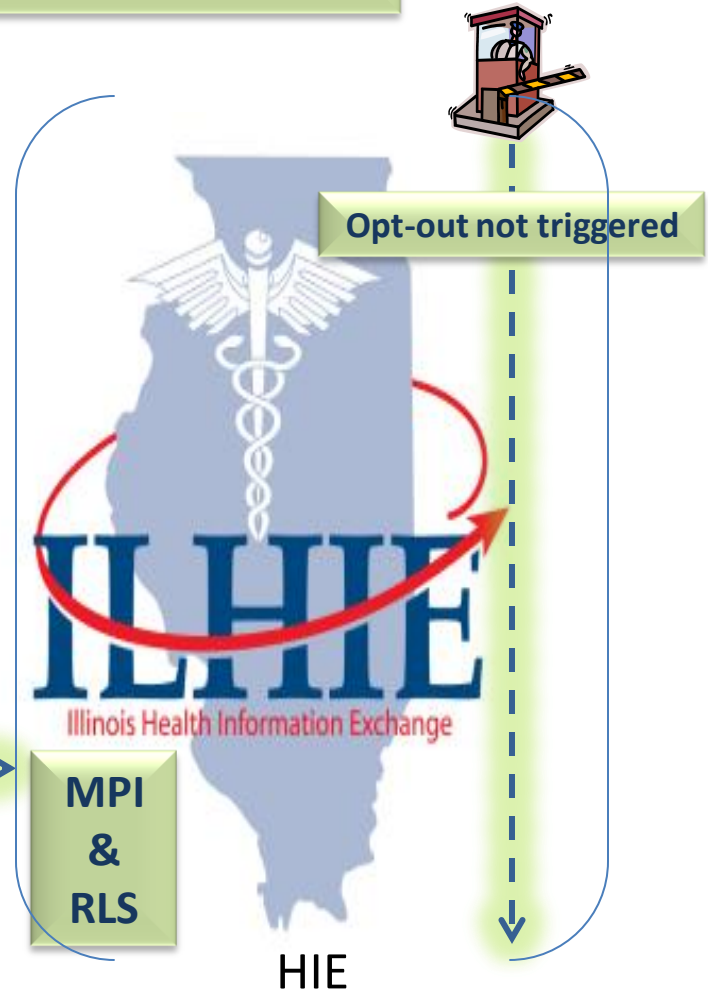
4. Patient demographic information sent to ILHIE

5. Patient data with PCP becomes accessible to ILHIE

PCP's EHR

Gen PHI

MPI & RLS

Opt-out not triggered

HIE
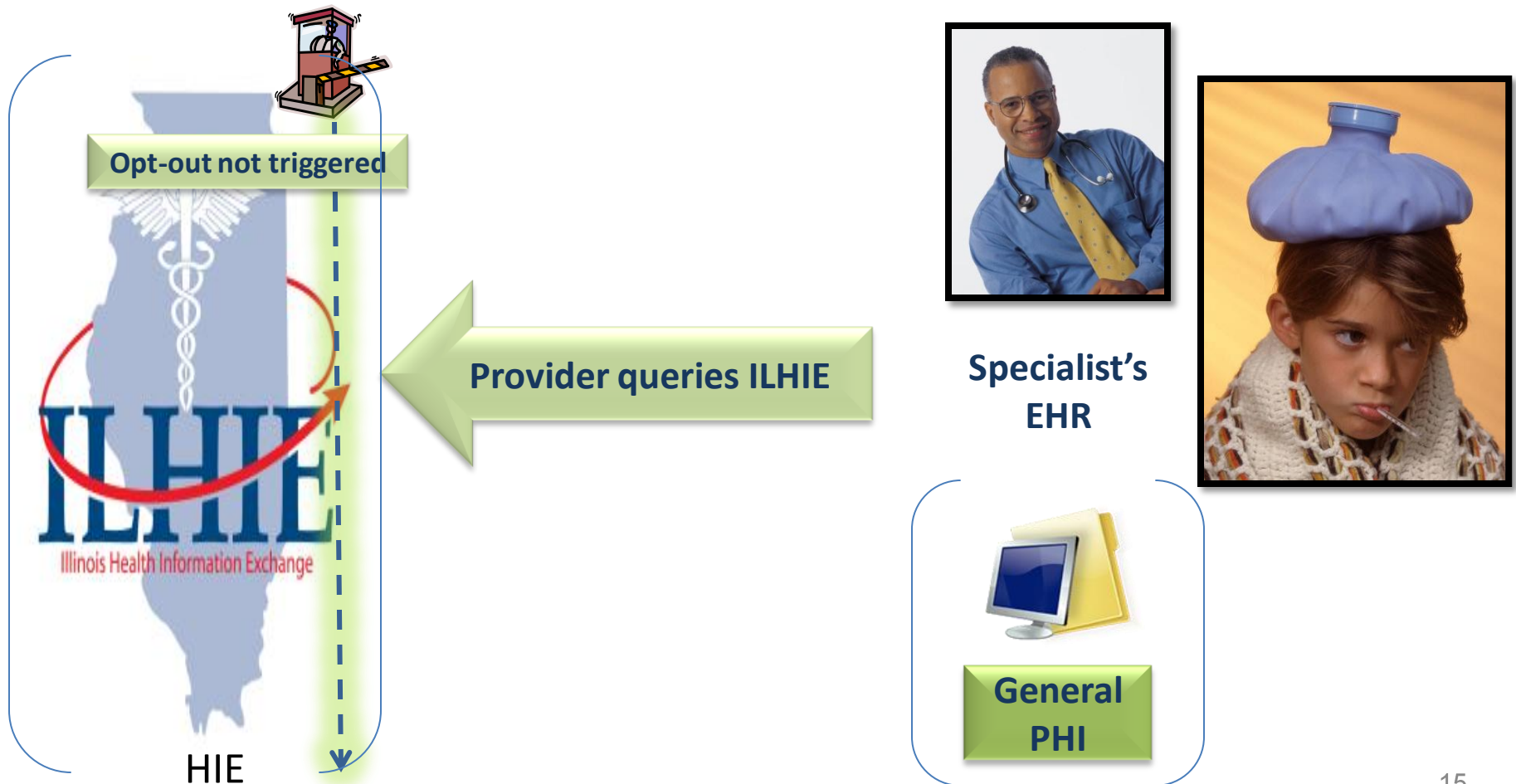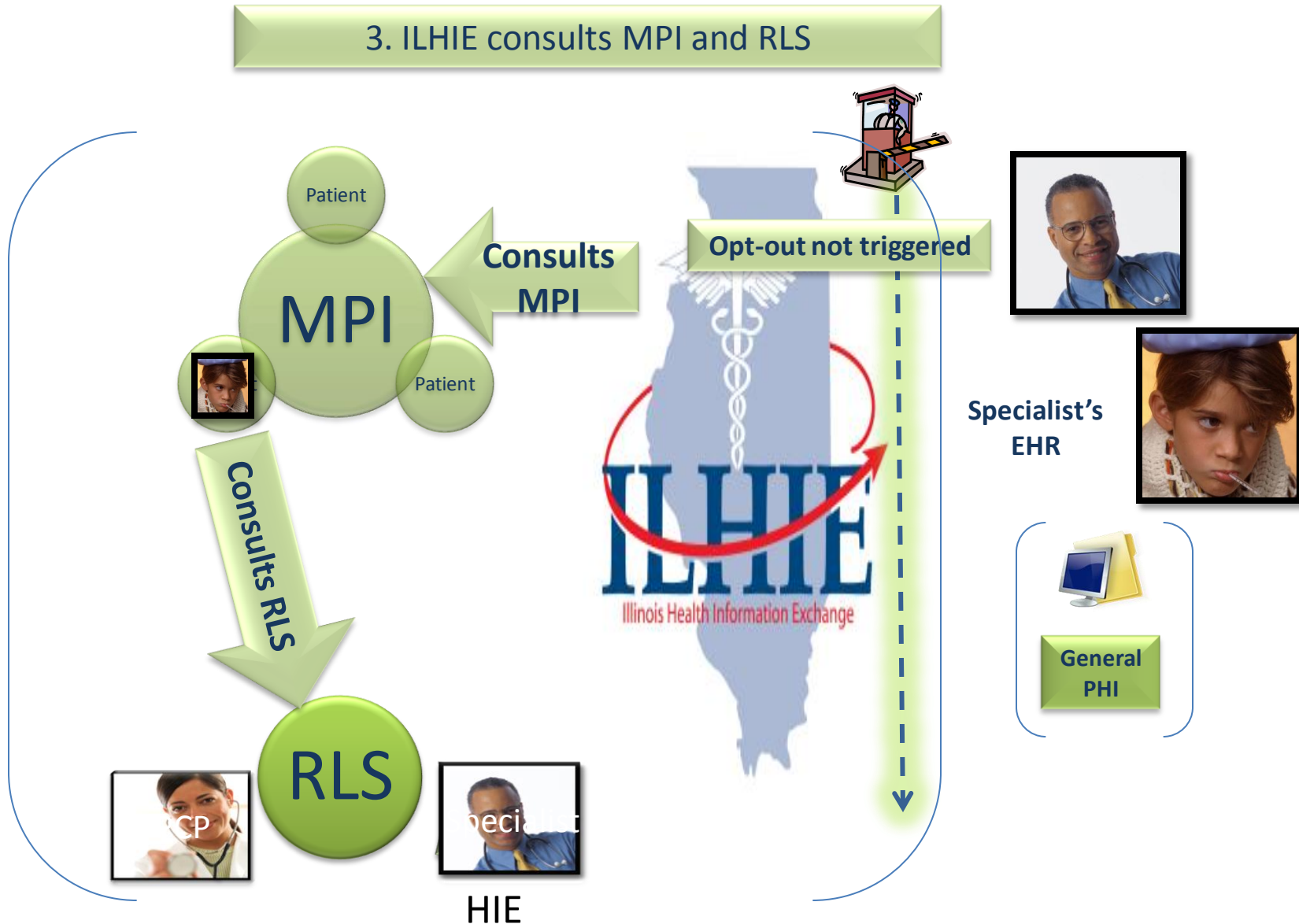
Use Case 1: Patient Participates in HIE

Stage 2: HIE Query /Response
Patient Presents at Specialist

1. Patient presents at ILHIE participating specialist

2. Participating specialist queries ILHIE for Patient's records

Opt-out not triggered

Provider queries ILHIE

Specialist's EHR

General PHI

HIE

Use Case 1: Patient Participates in HIE

Stage 2: HIE Query /Response
HIE Consults MPI & RLS

3. ILHIE consults MPI and RLS

Patient

Consults MPI

MPI

Patient

Opt-out not triggered

Specialist's EHR

Consults RLS

RLS

General PHI

HIE

Stage 2: HIE Query /Response
HIE Query of Participating Providers

4. ILHIE queries providers listed in RLS for Patient's data

PCP's EHR

ILHIE queries provider

General PHI

RLS

CP

Specialist

Opt-out not triggered

Illinois Health Information Exchange

HIE
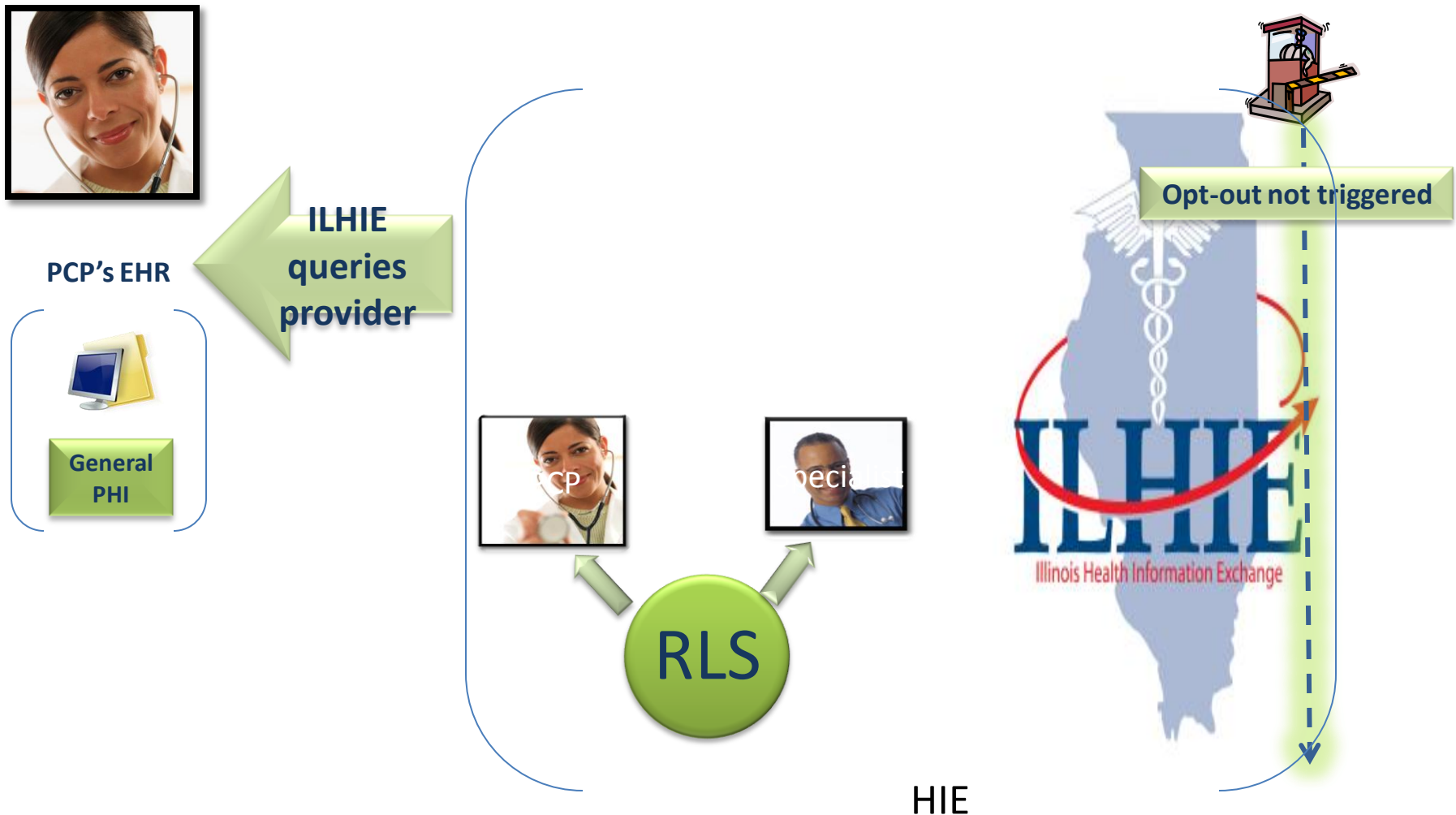
Stage 2: HIE Query /Response
Consolidated Patient Record (C32) Generation by HIE

5. ILHIE aggregates data received from providers
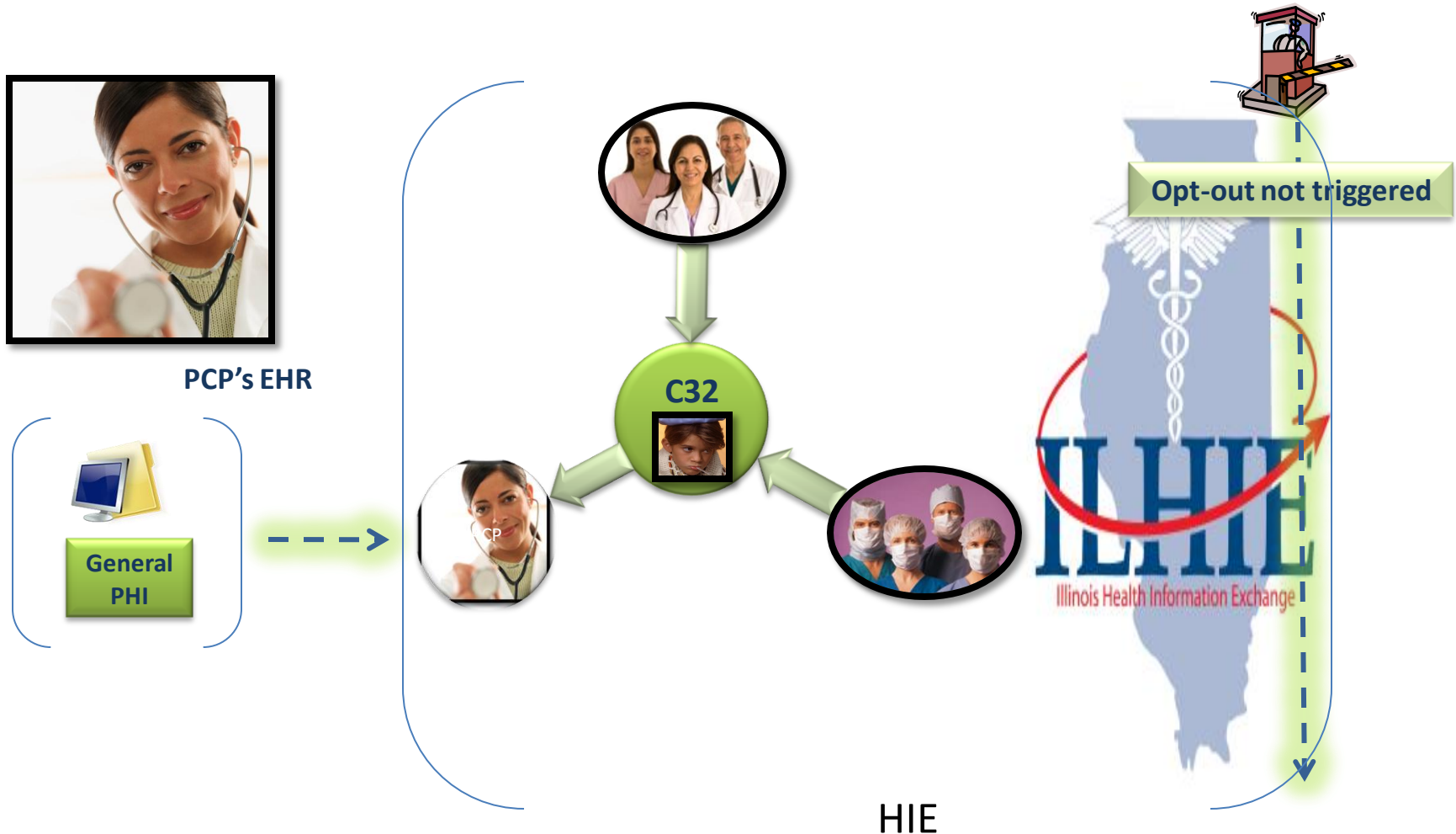
PCP's EHR

General PHI

C32

Opt-out not triggered

Illinois Health Information Exchange

HIE

Stage 2: HIE Query /Response
ILHIE Delivers C32 to Participating Specialist

6. ILHIE delivers consolidated C32 to requesting participating specialist

Opt-out not triggered

PCP's EHR

General PHI
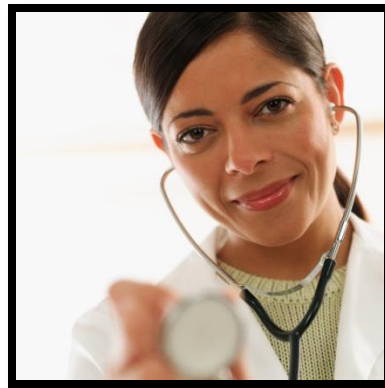
C32

Specialist's EHR

General PHI

HIE

Stage 1: Creation and Release of PHI
Patient Presents at Primary Care Physician

1. Patient presents at Primary Care Physician

2. Provider describes HIE and offers opt-out

PCP's EHR

Gen PHI

HIE

Use Case 2: Patient Opts-Out of HIE

Stage 1: Creation and Release of PHI
Provider Obtains Consent

3. Patient exercises opt-out

Opt-out notice to HIE

Opt-out triggered

PCP's EHR

Gen PHI
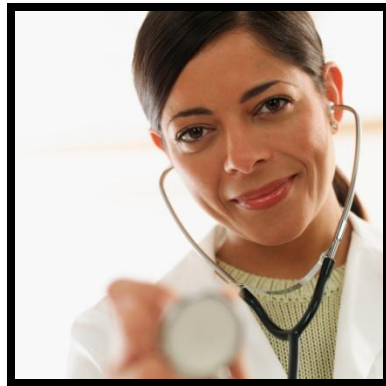
HIE

Use Case 2: Patient Opts-Out of HIE

Stage 1: Creation and Release of PHI
Release of MPI and RLS
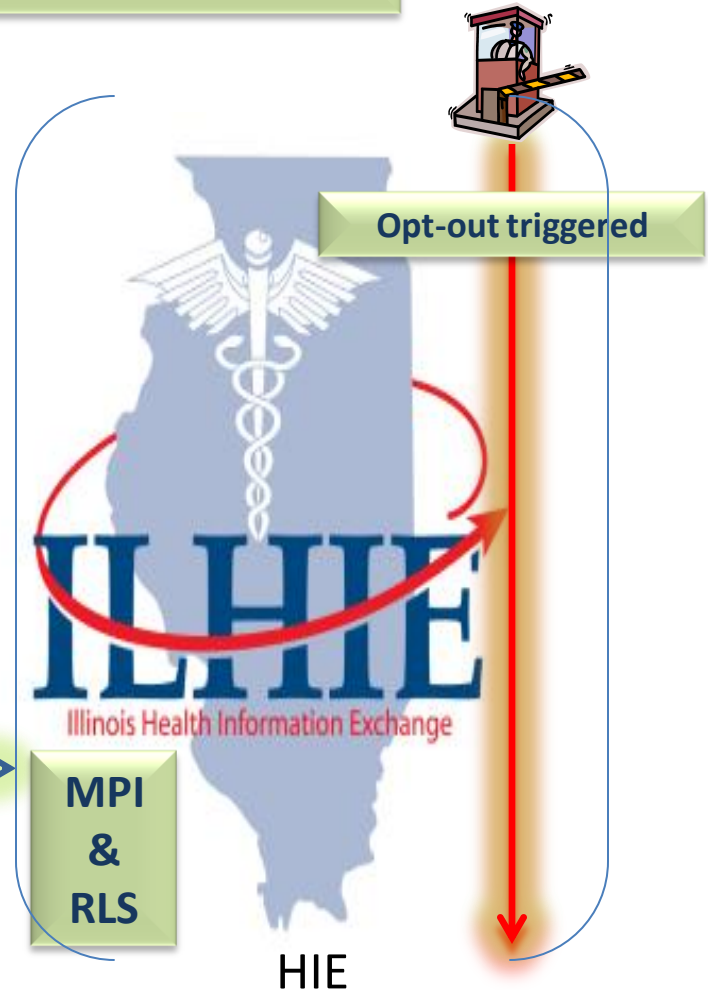
4. Patient demographic information sent to ILHIE
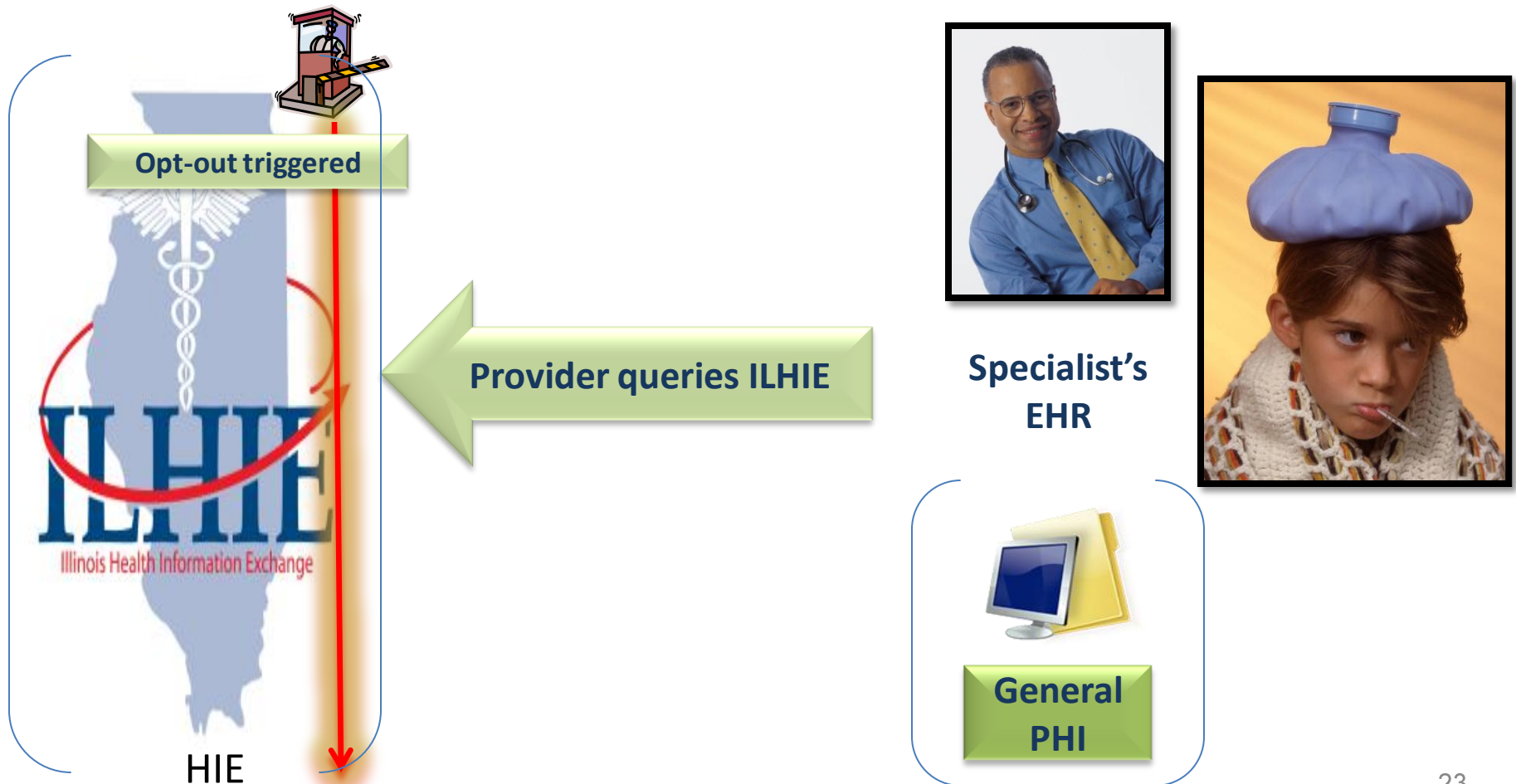
5. Patient data with PCP becomes accessible to ILHIE

Opt-out triggered

PCP's EHR

Gen PHI

MPI & RLS

HIE

Use Case 2: Patient Opts-Out of HIE

1. Patient presents at ILHIE participating specialist

2. Participating specialist queries ILHIE for Patient's records

Opt-out triggered

Provider queries ILHIE

Specialist's EHR

General PHI

HIE

Use Case 2: Patient Opts-Out of HIE

23

Stage 2: HIE Query /Response
HIE denies access to data

3. HIE returns "DATA NOT AVAILABLE" message

Opt-out triggered

"DATA NOT AVAILABLE"

Specialist's EHR

General PHI

HIE
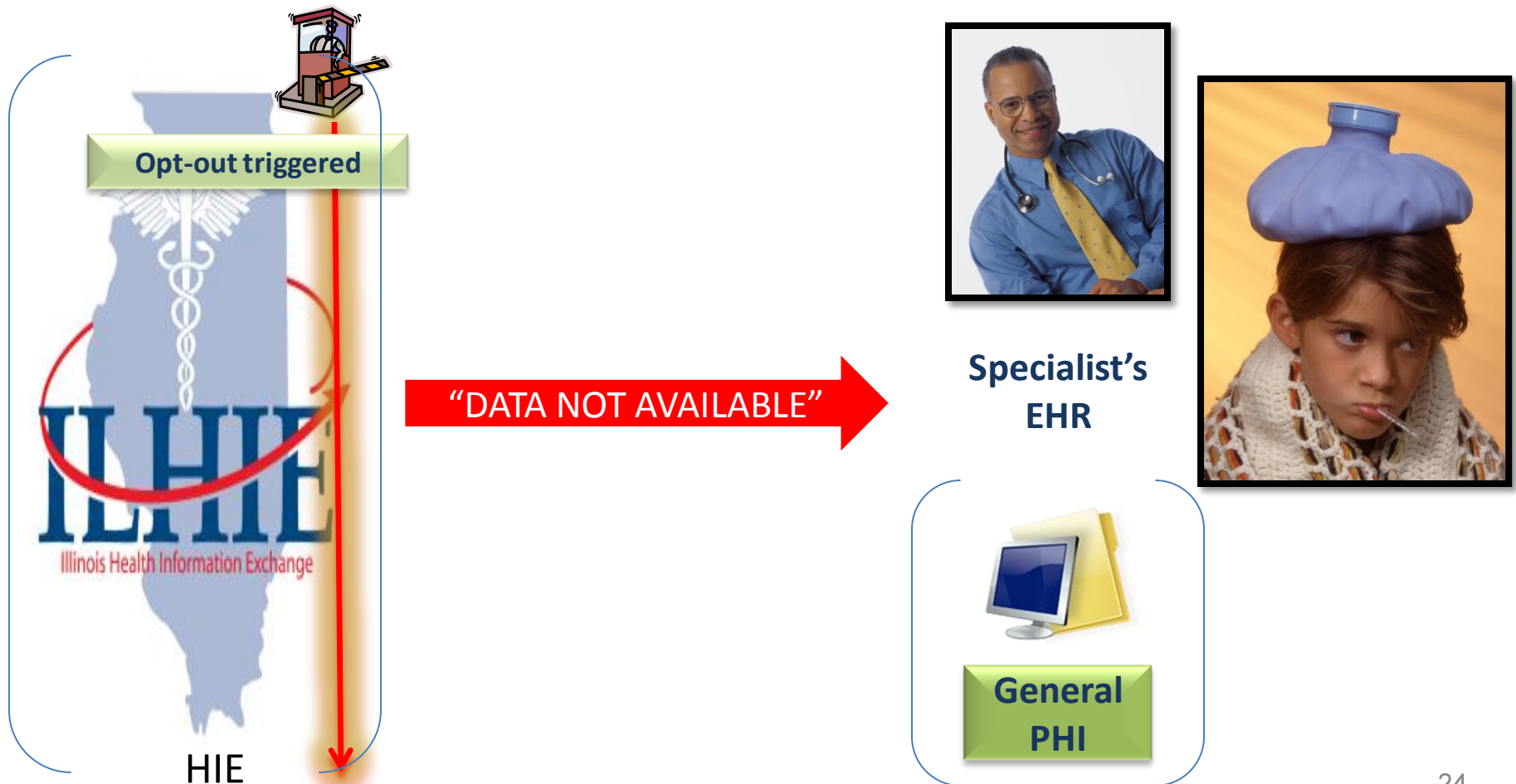
4. Participating specialist submits "BREAK-THE-GLASS" override to certify either:
   a. Patient medical emergency, or
   b. Patient provided consent

Opt-out triggered

Provider re-queries ILHIE with "BREAK-THE-GLASS"

Specialist's EHR

General PHI

HIE

Stage 2: HIE Query /Response
ILHIE Processes Query; Delivers C32 to Participating Specialist

5. ILHIE consults MPI and RLS; 6. ILHIE queries providers listed in RLS for Patient's data;
7. ILHIE aggregates data received from providers;
8. ILHIE delivers consolidated C32 to requesting participating specialist

Opt-out was triggered, but BREAK-THE-GLASS override

PCP's EHR

General PHI

C32

Specialist's EHR

General PHI

HIE
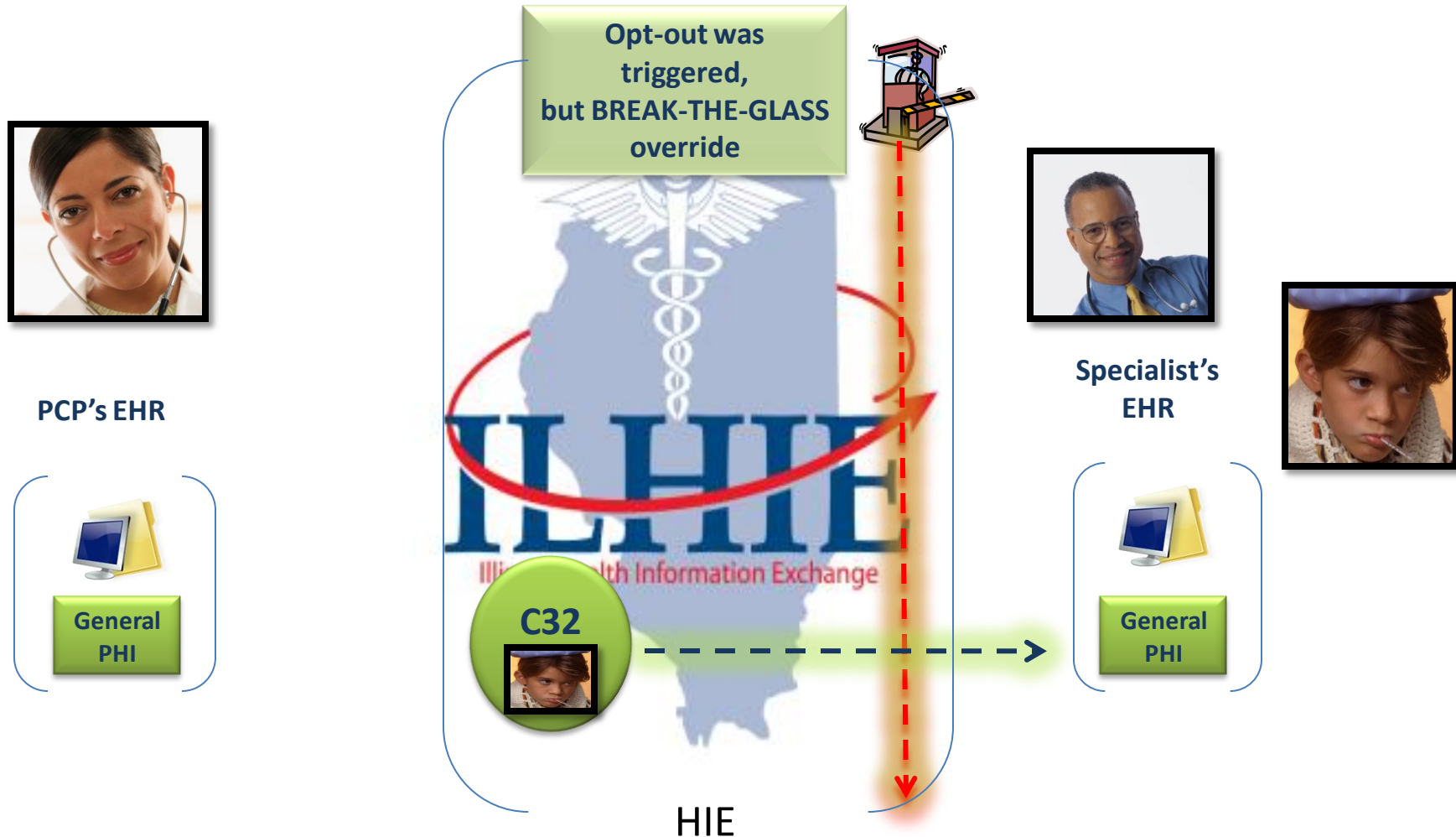
Legislative Proposal

- Specific statutory amendment being discussed with stakeholders

- ILHIE Legal Task Force Work Groups:
  - Behavioral Health Work Group: Laurel Fleming
  - Substance Abuse Work Group: Renée Popovits

Thank you for joining us

Mark Chudzinski, General Counsel, Illinois Office of Health Information Technology, Office of the Governor
e: mark.chudzinski@illinois.gov